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ABSTRACT

This report describes a 1988 site visit to Pride Industries, a private, nonprofit agency which operates an apartment program for individuals with developmental disabilities in Bismarck, North Dakota, through a contract with a regional office of North Dakota's Department of Developmental Disabilities. Pride Industries supports 34 people living in apartments, with residents obtaining services through the individualized supportive living arrangements (ISLA) program, funded primarily through the Title XIX home and community-based Medicaid waiver. The program provides either habilitation or personal care services. Each resident has both an internal and external case manager. The case study describes the structure of the ISLA program, methods for locating apartments, selecting roommates, selecting and training staff, developing contracts, scheduling, providing support services, and teaching to develop daily living skills. The case study also includes case histories of several of the residents. The report concludes with a discussion of organizational values, including leadership, openness to new ideas, mutual learning, reflectiveness, consumer control, optimism, and compromise. (JDD)

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Center on Human Policy

COMMUNITY LIVING FOR ADULTS IN NORTH DAKOTA: A CASE STUDY OF AN APARTMENT PROGRAM

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Community Living for Adults in North Dakota: A Case Study of an Apartment Program

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February 1989

This is one in a series of reports on programs and services that support people with severe disabilities in the community. The purpose of the series is not to evaluate programs or services, but rather to describe innovative practices in integrating people with disabilities into community life.

THE SITE VISIT

This report describes a site visit in October 1988 to an apartment program operated by a private, non-profit agency in Bismarck, North Dakota. Bismarck, a city of 50,000 people, is one of the few metropolitan areas in this largely rural state. As in all cities, Bismarck has a diversity of neighborhoods. According to one staff member, even the poorest neighborhoods in Bismarck are clean and well-kept up. He attributes this to the continued strength of the extended family in North Dakota and the recognition of the economic interdependence among all people.

Although this was my first visit to North Dakota, Steve Taylor, the director of the Center on Human Policy, is well known there based on his 1979 report on conditions at one of the state's institutions for people with developmental disabilities. The report received considerable attention within the state and was used by parents and advocacy groups to promote deinstitutionalization and the development of community services for people with developmental disabilities.

This report highlights a private, nonprofit agency nominated by several sources as having some of the best examples of community living for adults in North Dakota. It also describes North Dakota's use of the home and community based Medicaid waiver to support people with disabilities in the community.

THE AGENCY

Pride Industries is a private, non-profit agency started in March 1975 by a few members of the Bismarck community. Theresa Winbauer, Irv Reich, and Bob Vogel obtained a grant from the Aid Association of the Lutherans to start a

home and a sheltered workshop for six people with mental retardation. The organization was first named the Center for the Achievement of Potential.

Today, Pride Industries provides community living and work opportunities for 160 people with developmental disabilities from ten counties. Pride Industries also has a new grant for people labelled chronically mentally ill. The agency has a budget of two and a half million dollars and a total of 130 employees. The same Executive Director led the organization from 1979 through September 1988.

The organization has experienced steady growth since the filing of the ARC lawsuit in 1981. The lawsuit orders the closure of San Haven, one of the state institutions, and all but 250 people moved from Grafton, the other state institution, by July 1, 1989.

Pride Industries is moving from a reliance on group homes and sheltered workshops to supported employment and apartment living. Approximately half of the people supported by the agency now live in apartments and work in community jobs with support. Thirty-four people live in apartments they lease, mostly on the south side of Bismarck, and obtain services through the individualized supportive living arrangements (ISLA) program. As of September 1988, the agency provided support for thirty-one people in individual jobs in the community and thirty-six people on job crews.

The agency still operates six group homes with eight people living in each. Five people with mental health and mental retardation labels live in the other two homes, one of which was the first home of its kind in the state. Four of the homes were built through Housing and Urban Development funds and four are of older construction. Seven of the homes are located in Bismarck and one is located in Mandan, a town of 12,000.

NORTH DAKOTA'S HOME AND COMMUNITY-BASED MEDICAID WAIVER:

THE INDIVIDUALIZED SUPPORTIVE LIVING ARRANGEMENTS PROGRAM

As of September 19, 1988, 306 people in North Dakota live in what the state calls individualized supportive living arrangements (ISLA) funded primarily through the Title XIX home and community-based Medicaid waiver. The North Dakota Department of Developmental Disabilities started the program on May 1, 1987. The program is administered on the local level by the department's regional offices through contracts with private providers.

The unique aspects of the program include the capacity to provide services to a person in a home s/he owns or rents and the individualized nature of the service contract and funding. This is one of the few places in the country with a contract negotiated for each individual person. Payment rates tied to the individual person are developed only after the person is identified, the home of the person is selected, the roommate, if any, is chosen, and the services the person needs are determined.

The contract with the private provider can be for either habilitation services or personal care services. The cost of a qualified mental retardation professional (QMRP) is not covered in a personal care contract and expectations regarding training are not as structured. The initial contract period for an individual is generally for three months. Contracts are then renegotiated for a period not less than three months and no more than a year.

Service hours paid for through the contracts can range from a few hours a week to twenty-four hours a day. The home and community-based Medicaid waiver is used to finance the costs of the direct services hours (at a standard rate of $5.59/hour and up to 25% fringe benefits), the standard qualified mental retardation professional (QMRP) and casemanager costs (at approximately $50

per month per person for each), and the $200 per month per contract standard administrative reimbursement.

The state can also provide a state room and board supplement, if necessary, to subsidize the person's housing and related costs. Typically, if the actual costs of a person's room and board expenses are lower than the person's monthly net income, there is not a supplement. Items such as telephone, transportation and recreation are not always considered a necessity by the state.

According to the Department of Developmental Disabilities, as of September 1988, the per diem for these residential services range from a high of $253.53 to a low of $12.48. The average per diem at Grafton is $197.47. Based on a sample of 254 people in the ISLA program, the Department of Developmental Disabilities calculates the average daily rate prior to placement to be $39.81, for the first three month contract at $34.56, for the immediate past contract at $34.27 and currently at $32.90.

In reviewing the costs, it is important to note that most of the people supported in these homes and apartments moved directly from a community group home into the program. It is possible, however, for a person to move directly from San Haven or Grafton, the state institutions, to a place of his or her own and receive services through the ISLA program.

As required by the lawsuit, each person has both an internal and external casemanager. The external casemanagers function out of the regional offices. They are responsible for locating programs, monitoring, systems coordination, provider support and transdisciplinary team participation. The internal casemanagers, staff of the private agencies, initiate the individual habilitation plan (IHP) meeting and coordinate services.

From the viewpoint of the Department, the ISLA program is fiscally,

programmatically and administratively successful. They see the only shortcomings of this funding mechanism as the greater difficulty in administering the program and the auditing for cost as opposed to settlement.

THE INDIVIDUALIZED SUPPORTIVE LIVING ARRANGEMENTS PROGRAM AT PRIDE INDUSTRIES

Starting the Program

Pride Industries was one of the first private agencies in North Dakota to be involved in the individualized supportive living arrangements (ISLA) program. Thirty-two of the thirty-four people in the program moved from group homes to their own apartments. Pride has closed one group home and about two additional people a month move to their own apartment.

The Supporting Structure

Larry* is the associate director who started the ISLA program at Pride Industries. Since the program has grown, he has hired additional staff to help him with the ongoing training, supervision and administration of the program. Sheila is program director. She works with Steve, Sandra and Cory who each supervise from 8-14 part-time staff.

Of the six social work positions in the agency, one and a half are assigned to the ISLA program. The social workers are considered to be the internal casemanagers and are responsible to another associate director, Jim.

The Board of Directors is in the process of selecting a new Executive Director. Bob, one of the current management staff, is in an acting director

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*All names used in this report are pseudonyms

role. Larry, Bob and Jim form the core management team for the agency.

Making the Individual Decision

The individual habilitation planning team (IHP) must make a referral to the ISLA program. The team consists of the person with a disability, his or her family, the casemanagers and professionals who are involved with the person. The team figures out what the person will need in the community and must do so in detail.

The referral is reviewed internally by Larry and Bob to insure the person's needs can be met. As Sheila said, "No one has been turned down yet. Figuring out how to do it can take sometime. Waiting more a sense of how we are going to do it."

Sheila explained that six months ago they would not have been able to support a couple of the people who recently started in the ISLA program. With experience, their own capacity to support people who have greater needs is growing. It has also taken some time for the individual teams to gain confidence in the program. Referrals are now increasing as parents and direct service staff know that people are supported well in their own apartments.

Finding a Place to Live

The specific apartment is identified before the contract for funding for the individual person is finalized. All people in this program through Pride Industries lease their own places. The organization feels this is important because it is closest to what is typical in this society. The agency has not pursued strategies on the actual purchase and ownership of homes by people with disabilities and/or their families.

I asked Larry to describe how people went about selecting where they

would live.

> Michael and one of the staff say let's go apartment hunting. They go through the paper, figure out how much it is, can he afford it...the same way you and I would go for an apartment. If they like it, they get it.

On a financial basis, the agency believes that leasing is the most practical way to develop the program. First, most people living in their own places are eligible for housing assistance through the federal Section 8 program. Since the waiting lists are long, Pride Industries helps a person apply for assistance even before s/he decides to obtain an apartment. If the person moves before the subsidy is available, s/he may be able to obtain a temporary state supplement for housing costs. Second, the organization is not responsible for damages as they would be if Pride rents and then sublets an apartment to a person. Third, rental housing is generally available in the Bismarck area. Locating housing near work is the major issue since Bismarck has no public transportation system.

Selecting a Roommate

The state office of developmental disabilities encourages people to live with a roommate for fiscal reasons. The specific roommate must be identified before the contract for funding for the individual person is finalized. As the regional representative explained, people with mental retardation "have to live within the real world. Same principles - I would not want a roommate, but if I needed one financially, I would get one - also apply."

Sheila explained the organization made a lot of mistakes in matching roommates in the beginning. In at least three situations, they needed to find

different roommates or different apartments. Now they are getting better at the matches and people are choosing their roommates.

Recently, people who need to live alone are able to do so. From the viewpoint of the state office, it is not enough that a person wishes to live alone. The agency must document that living alone is a necessity for the particular individual. The state can authorize a room and board supplement to make living without a roommate possible for people who otherwise could not afford to do so. Pride currently provides services through this program to two people who are living alone in their own apartment.

It is possible for three people to live together in the same home if they know each other well. This, however, is discouraged by the state office to de-emphasize the problems with congregate living.

Selecting and Training the Staff

To have staff hired and ready, Larry needs to know between two to six weeks before a person actually moves. The staff who will work with the person in his/her own apartment get to know the person while s/he is still living in the group home. Larry says "the staff and the person with a disability become a team." In other words, they work closely together and make a lot of the daily decisions together.

Larry believes that hiring good, sensitive people makes the difference. He said "I know what qualities I like in a person. Resumes mean nothing to me. I can size up a person. If they have common sense, I hire them. I promote good people. I take gentle type people, not those that are hard. I like to take students, more educated, less judgmental, more time."

Most of the part time staff are students at the University of Mary or Bismarck State. The work fits in pretty well with a student schedule. When a

new staff member is hired, s/he shadows an experienced staff member until the new staff member is comfortable. The main emphasis is on helping the staff member learn about the individual person, to really make it an individualized plan. Finding good staff, especially on a 24 hour basis, continues to be one of the major challenges.

Some of the training involves helping the staff understand the field of developmental disabilities, why what they do is important, what is the difference between group living and apartment living, and what it means to help a person move from dependence to independence. They also cover what Steve calls "the little stuff" - the forms, the need for documentation to show accrediting agencies and the lawsuit, and helping people to understand the why behind the extensive documentation.

Developing the Contract

Before Larry negotiates a contract, he gets input from the team and the residential staff on the services and the number of hours of support the person will need. Larry himself also knows the people quite well if they have been involved in the agency's service system. Referrals from the community-at-large are much more difficult to figure out.

Figuring out the hours is a very time consuming process. The team needs to look at a variety of issues including what is scheduled during the day, whether the person can stay alone at night, whether the person can get up by him/herself, if s/he needs someone there on the weekend as opposed to the day, etc. The situation must be looked at practically minute by minute.

Larry and the state representative at the regional office come to an agreement on how many hours the state will reimburse the agency for coming into the person's home and working with the person in the community. The

initial contract is for three months because it is difficult to determine how the person will react in a new environment. The number of service hours varies from individual to individual. The expectation on the part of the state is the number of hours in the succeeding contracts will decrease.

Funding the Services

As of September 1988, Pride Industries had ISLA contracts with service hours ranging from 13 to 138 hours/month/person. Two of these contracts are personal care contracts. Several people receive room and board state supplements. The agency hopes to increase the number of service hours to support people with severe disabilities up to a 24 hour per day basis.

Writing the Job Description

Larry explained they wrote the job descriptions after the staff were on board for six months. Everyone brainstormed on what they actually did. Larry's philosophy is what needs to get done, will get done. In other words, what people need determines what the staff do.

Planning the Schedule

Once the number of hours and kind of services are approved and the staff hired, the individual staff member and the person with a disability get together and make out a calendar for the week at times convenient to both of them. What happens during the week is up to both the staff member and the person with a disability.

Larry explained it is important to be flexible especially when working with college students. It is up to the individual staff member to find their own replacement. Supervisors will help out, if needed. This is one of many

ways of maintaining morale. Larry said over time there is less need for the supervisors to play this role. "As they (the staff) know the person, they take more ownership. They don't want to let the person down."

Supporting the People

One of the strategies this agency uses is to locate the individual's apartment near the home of a staff member or another person known to the individual with a disability. June and George, for example, live close to people who provide services regularly, services that are often intangible.

> June lives in a basement apartment and Liz lives upstairs with her poodle Peaches. Liz sees June for about twenty minutes each morning to help her get started with the day. Each evening when Liz gets home around 9 pm, they visit. Liz is paid a flat base of money for the security and continuity she provides to June. The actual services she provides, however, may vary over time.

Another important strategy is to try to find the right match between the person with a disability and the staff person. There is generally one primary staff member for each person.

> Tom is real easygoing. He is very accepting if things don't happen the way they were planned. Oh, we'll do it tomorrow. He already had somewhat of a relationship with George. George perceives him as a buddy or at least it could develop that way...We waited until we had the right staff.

A third strategy used to support people in their own place includes the

use of safety devices and emergency systems.

David has two safety systems in his apartment. The FAST system is a button in his bedroom; it rings at the medical center and contacts one of the four people on David's list. If they are not available, an ambulance comes and the workers check the vial in his refrigerator. The vial contains emergency information including contact people and health data. David has a hearing impairment and uses an emergency device called a silent pager. The telephone, fire alarm and door are all programmed on this watch-type device that he wears on his wrist. The device shakes and a red light comes on next to the number so David can respond to the fire alarm, telephone or door.

Teaching in the Home and Community

Some of the time staff spend with people in their homes and in the community is for teaching formal goals and some of the time is more informal.

Statements of achievement, known in other organizations as goals, are determined through the individual planning process each year. Formalized goals have a baseline and specific teaching techniques, including prompts and reinforcement schedules. Teaching in areas such as budgeting, menu planning and apartment maintenance are often formalized goals with the specific plan varying from person to person. These are all taught at the time, place and manner where the skills are typically used. For example, Robert and Trish were cooking a casserole for the evening dinner when I visited. Although I could tell Trish knew more about the recipe than Robert, cooking the meal was a shared activity.

All services, including transportation back and forth to the grocery

store, must be stated explicitly in the plan or they will not be funded by the state. Inclusion in the plan, however, does not insure the service will be funded. The plan also lists service objectives the staff need to do, such as help with obtaining food stamps.

The agency also assists a number of people living in the apartments with medications. This is seen as a necessary part of living in the community. For example, George has diabetes and self-administers insulin shots. A staff member will be at his apartment at 7 am, 4 pm and 9 pm to help him with the medications. George also has learned to use a machine to monitor his own sugar levels. As another example, a person on psychotropic medications periodically refuses to take them. When that happens, a staff person he trusts comes in and counts the medications with him.

Teaching also takes place on a more informal basis, often by taking advantage of natural learning opportunities as they arise in the course of everyday life. For example, Debbie fixed an eight layer salad for dinner, adding waterchestnuts for a change. After dinner Debbie made sundaes for all of us. Areas like recreation are also more informal. The staff member will try to figure out with the person what s/he might enjoy doing. The staff try to keep informed on what is going on in the community and to be sensitive to the individual tastes of people. For example, some people prefer activities like movies while other people like June enjoy more active sports like soccer and basketball.

The formal services people receive, as well as more informal supports, differ from individual to individual, including the time of the day or week and the type and amount of service. On a daily basis the person with a disability and the individual staff member determine when services and activities will occur. The emphasis is on insuring services do not become too

intrusive in the person's life.

Supporting the Staff

In addition to training, the organization creates opportunities for people to stay in touch with one another. These can include social occasions such as parties and picnics where both people with disabilities and staff members participate. Larry and Sheila also attend monthly staff meetings. Meetings are often seen as opportunities to brainstorm on significant issues. The organization emphasizes staff support including supervisors taking on direct service responsibilities when needed, schedule adaptability based partially on staff needs, and program changes based on staff input.

Evaluating the Staff

Formal evaluations are completed at three, six and twelve months. The first months are considered important times to give feedback and to discuss whether the work fits the staff member's expectations. Each staff member rates him- or herself before the meeting with her/his supervisor. Larry says it is particularly important for staff to hear out loud good things about themselves.

Evaluating the Program

Other than accreditation and external casemanagement, there is no formal way of examining the quality of life of people in the program. This is an area the agency is exploring.

A FEW OF THE PEOPLE

DEBBIE AND HER FAMILY

Debbie is a young woman who has a wonderful sense of humor, strongly believes in her religious convictions, appreciates and enjoys her family, describes herself as an independent voter, makes delicious sundaes, enjoys the band Blackwood and wants a better and more interesting job. She is a sister, a daughter, a member of the Alliance Church, a friend, a neighbor, a worker, a hostess and a tenant.

On March 21, 1975 at the age of 20, Debbie's life and the lives of her parents, two older sisters and two younger brothers changed. Debbie had an aneurism. As Debbie described it having the aneurism and what followed "was scary to say the least." The doctor warned Mrs. Williams not to be surprised if their marriage ended in divorce. As Mrs. Williams said,

> If you didn't have religious morals, it would be the easiest thing to do. Our whole lifestyle on the farm changed...We gave up our bedroom, needed a hospital bed. We were up every hour day and night. Debbie's faith has healed her. The doctors couldn't believe it. Our choices at Grand Forks was a nursing home or home. No other options.

Since her aneurism, Debbie spent months in the hospitals in Bismarck, Rochester and Grand Forks, went to the Missouri Slope nursing home for day care while living with her family, in 1983 to an intermediate care facility, and then in 1984 to a transitional living facility operated by Pride Industries. Since July 1987, Debbie has lived in her own apartment in a complex offering the conveniences of a sauna and outdoor swimming pool. Debbie

was the fifth person to receive services from Pride Industries through the individualized supportive living arrangements program.

Debbie explained she still has problems with comprehension and time sequencing. She uses timers to keep herself on schedule. She takes tegretol and hopes someday to be off medication completely. Debbie doesn't see very well from one eye and can lose her balance. Her work supervisor says she still has trouble focusing on a task. Especially under stress, Debbie may show a variety of repetitive behaviors.

Debbie's apartment is carefully decorated with finishing touches gracing each of the rooms. In the bathroom, the radio is turned on, a small embroidered picture is on the wall, and the large, plush orange towels and matching two layer shower curtains add a touch of warmth. In the livingroom, a large basket with brown and beige feather-like plumes extends delicately from the corner toward the comfortable, modern style sitting area. Debbie says the large intricate macrame is a gift from her sister. Her mother helped her to decorate her place.

When I asked Debbie what she liked about living in this apartment, she replied "everything compared to the other living situations." Her younger brother Derek said he was "jealous, wouldn't you be?" He said since Debbie has moved to the apartment, "it gives her enthusiasm to get things done." Cleanliness and neatness are an important family value. Mrs. Williams said "at the group home, it was tornado city, depressing to me and the people who live there...She (Debbie) has a lot of company here. She'll have people in for a meal. I hated to go to the group home."

Mrs. Williams described her current feelings about Debbie's move to her own apartment:

I think it's the best idea there ever was. I was surprised myself how well she is doing - from way back, until now, a world of difference... Since she is living in her own place, nothing she can't do if she sets her mind to it. She's an achiever. When she sets her mind to it, she is determined to do it...Her place is clean, we can just drop by; she is prideful of what she has. If Debbie doesn't like something, she doesn't hesitate to take care of it herself.

Debbie added "I'm glad the ISLA program came along when I needed it."

GEORGE'S MOVE TO HIS OWN APARTMENT

George, a man in his 50s, was moving into his own apartment in a small stucco house the evening we met. Sarah, his friend, was washing the dishes as Tim, one of the ISLA staff, unpacked them. He unpacked so many, Sarah finally told him good naturedly to stop already. George would move between drying the dishes, letting Tim know where things belonged, unpacking boxes and showing Sheila and me his apartment and his new purchases. He also stopped long enough to answer the door and meet one of the neighbors who stopped by to welcome him to the house.

Until 1985 George spent most of his life in institutions going back and forth between the state hospital and Grafton. He has been diagnosed by both the mental health and mental retardation systems. One staff member described George as having a basic demeanor of "What are you going to do to me?" Given his life experiences, taking responsibility for his own life is a struggle for George. George has an alleged history of abuse of females and violence. George also has diabetes and must have insulin shots.

George seems like a pretty cost conscious guy who wants to make sure he

gets a good deal on his purchases. He respects Sarah's taste. She helped him pick out items, like his soft new blue blanket, for the apartment. He also teased Sheila, who lives down the street from him, saying it was okay if she stayed in the neighborhood. He warned me if I was going to have fun in Bismarck to stay away from the liquor. He doesn't approve of people doing things like that. George enjoys listening to the radio, riding his bike and spending time with Sarah.

George said he's very pleased with his new apartment. It's a spacious one bedroom in a nice neighborhood. When the housing subsidy comes in on November 1, the apartment will only cost him about $100/month rent. As he unpacked, he carefully pressed out the creases in the tablecloth and placed his costly and self-purchased medication monitoring machine in a place where no one could destroy it. He tried out his phone ("It works. It works.") and decided after much discussion the cost of $12.00/ month was worth it. Tim and he will be picking up a couch tomorrow. He wants to buy an ironing board, but he needs to save up money before making any additional purchases.

MICHAEL AND ROBERT'S APARTMENT

Michael is a pretty reserved fifty year old man who believes family is important, enjoys German food, is proud of his possessions, and is hoping to find a woman with whom he can settle down. He currently works in the woodworking area of a sheltered workshop, but prefers dishwashing. Michael previously worked at a restaurant and hopes to do so again someday. He has a friend Chas who lives in a nearby group home. They enjoy visiting and going bowling together.

Michael comes from a large family. He has four sisters, three living out of state, and two brothers, one in Florida, and one in Fargo, North Dakota. He

sees his sister Mary once a week or so, visited his brother Phil only once, and flew to Florida for a vacation at David's home. He has a photograph album with pictures of his tour of Cypress Gardens and of David's family. A black and white photograph of Mary, his sister Roseanne and his mother sits on the nightstand near his bed.

Michael spent sixteen years at Grafton starting at the age of 27. In December 1978 he moved to a group home for five years, to another group home, to a foster care placement for about a year and now to his own apartment. Michael likes living here.

Michael shares an apartment with Robert. Robert graciously brought me a cup of black coffee while Michael and I looked through his photographs. On the kitchen wall is a framed aerial photograph of the home where Robert grew up. Robert and Trish, one of the staff, also put together a grocery list. At one point, he and Trish rushed out of the apartment. It was raining and the car windows were down.

Michael and Robert knew each other from a nearby group home. They both enjoy going to a restaurant on Main Street. Neither of them are pleased with their new landlord and neighbors. One man complained about noise they made at a time when they weren't even at home. This same man used Michael's parking space without asking him. Michael feels it is his parking space whether he has a car or not. They are not sure if they want to stay in this neighborhood.

DAVID AND HIS FAMILY

David's major love in his life is his exact-to-scale models of homes constructed by him from blueprints or from visits to open houses. In four days he can make a detailed replica complete with wiring and landscaping. He is

justifiably proud of his creations. His father explained David watched the construction workers in the development where he grew up. David noticed when the workers made a mistake, like a problem with wiring, sometimes before they realized it. He is perceptive in noticing those types of details.

David is 27 years old and the youngest of four children, all the rest married. His parents live about 100 miles north of Bismarck in a town called Minot. He keeps in touch by phone and sees them about once a month at his place and once a month in Minot. They have a very close relationship. As his father said, "He's given us so much happiness - hard times too, but he's taught us a lot." David's sister is expecting a new baby. He hopes it will be a boy. He gets along well with his nieces and nephews. David has some cousins in town who stop by his apartment. Three friends of the family also bring over goodies.

David is an easygoing person who genuinely seems to enjoy people and likes things neat and in their place. He has a good sense of direction, but poor balance due to cerebral palsy. He likes to play PACMAN on his computer, has a huge collection of tapes, works at a job recycling cans and paper, enjoys fast food and shopping, wants to go to expensive places to eat if his brother will buy, goes bowling twice a week, likes to take out library books on houses, and attends church every Sunday. David is careful with his money, saving for one item before planning on another. He cooks well except when he's in a hurry and turns the temperature too high. His major form of transportation is his three wheel bike.

David uses Amerisign and his parents wish basic sign language was taught as a second language in schools. David can also draw pictures, uses a variety of gestures and facial expressions to get his point across, uses two hearing aids, can read lips to some extent, and has some speech - more understandable

as you get to know him. As his mother said, "He has a lot of abilities we don't even know yet." People who know him admire his patience with them. He sometimes wants his mother to bring a specific item when she comes to Bismarck. His mother says it must be so frustrating when she shows up without it. Denise, one of the staff, will sometimes be outside the house before she figures out what David meant.

David's parents reluctantly agreed to his move to an apartment. As Mrs. Jamison said "I didn't believe it myself. It was traumatic." When David moved into the apartment, they stayed in his second bedroom for a week to see how it all worked. They met all the people who would work with David, helped him hook up his lights and television, paid his fees and checked out the emergency response system. The staff could have done some of those things with David, but his parents wanted to check things out firsthand. Although his parents didn't trust the system, they learned to trust the staff. The staff worked well together and were interested in David.

This specific apartment was very important to David's parents as well as David. As Mrs. Jamison explained "when we got here the manager was so pleasant. He accepted us and he accepted David." David's parents know David matters to the landlord and that makes a tremendous difference to them. The landlord considers David a wonderful tenant - one who is fussy enough to make sure the landlord keeps the hallway clean.

David's apartment is comfortable with furniture brought from his parents' house, found at garage sales and bought new. He returned a large couch to Pride because he thought it took up too much space. He is purchasing piece by piece a new kitchen set with comfortable cushioned roller chairs. His mother bought the drapes for the apartment. David has a huge picture of a red convertible over his bed and as his father kidded him, a few pictures of women

on the side wall.

The FAST system, silent pager and speaker phone with memory - all types of emergency response systems - also provide Mr. and Mrs. Jamison with some sense of security. As the Jamisons explained, they know they are not going to be around forever. They believe it is better for David to start now doing things more on his own. However, as Mrs. Jamison said,

> Many times I've thought about coming and taking him home. Being a nurse, I want it the way I want it. It is difficult to let go. He wants independence. He does not want to go home.

Mrs. Jamison recognizes that David has made an important decision about his life. Sometimes that decision is a difficult one to accept. Mrs. Jamison explained it was important for David to have supports, but they need a support system too.

JUNE'S FIRST APARTMENT

June, who is 25 years old, moved to her basement apartment in September 1988 from a group home in Mandan. The apartment is located in a two story mason house in a middle class residential neighborhood in Bismarck. June's apartment is furnished much like many young people's first apartments. The older, saggy couches are covered with throw covers, the carpeting is worn and the furniture is a collection of pieces probably found at garage sales. A 1,000 piece jigsaw puzzle is partially started on a table and the living room seems lived in.

Her family, having friends, her independence and her participation in a day program all seem important to June. June travels the two miles to see her

mother about every other weekend. They talk by telephone two or three times a week. June also has one sister she sees for lunch and a few brothers. Three days a week, June attends a program where she participates in relaxation and discussion groups and in activities like ceramics and woodworking. June also plays soccer and basketball and is changing teams due to her move to a new city. June also places almost constant emphasis on food.

June lived at home until she was 21 years old and then moved into a group home for four years. Her mother explained the move was hard on both of them, but they adjusted. June was described as a disruptive force in the group home; it was not a good environment for her. June can be very protective of people she sees as friends, hitting and kicking someone who slights them. She also has been described as demanding and as a person who has trouble controlling herself. She is a very high energy woman.

Liz, one of the staff, and her poodle Peaches live upstairs in the same house. Liz primarily is there to provide the overall security of having someone around that the team believes June needs. Shortly after June moved to her apartment, the staff person who was working with June left. This was described by Sheila as a hard blow. As Sheila said, "We are trying to have an environment that is more effective for her. She has not reaped the benefit yet. She does not feel secure there yet." Or as June's program coordinator said, "She'll do fine once she's been there awhile."

ORGANIZATIONAL VALUES

LEADERSHIP

In this organization, we see a translation of the personal values of people such as Larry and Sheila into an organizational climate and into the basic daily decisionmaking process. This ability to translate one's values

into an organizational climate is one aspect of leadership.

This organization's practices are not independent of people like Larry and Sheila, but arise in part because of their values. Sheila described one of the reasons she values Larry.

> He's always been real fair and a wonderful supervisor. He has a good balance between the staff and the clients. Everyone has an importance to him.

The next section describes some of the personal values impacting on the daily decisions in the ISLA program. Larry and Sheila realize they as individual people influence the program and the organization. The organization without them is not the same organization.

CORE VALUES: A CLIMATE FOR INDIVIDUALIZATION AND CHANGE

The most striking aspect of this program is the strong set of personal values setting a climate for individualization and change. The values apply to people, whether they are staff, people with disabilities, parents, professionals or the community-at-large. These values impact on the myriad of daily decisions made in the program.

OPENNESS TO NEW IDEAS

The most common theme in the interviews was the emphasis on the openness of this organization to new ideas.

> Their biggest strength is their willingness to do things. They're not trenched in tradition...Pride has been real ingenious in doing different

things.

No solidly one way to do things. Most of the people here are interested in new ideas for doing old things or new things.

This openness to change has enabled Pride to come up with new solutions to complex issues. As Sheila explained, most of the issues in this field are grey and the solutions cannot be black and white. "In this field, (we) need to try a lot of new things - treading new ground all the time." A lot of times, trying new things like the ISLA program is done by trial and error. Sheila explained, "Everyone should have what Debbie has. We just don't always know about the support. We didn't know it until we did it. When we tried it and did it, we knew it was right."

Process is an important part of what goes on in this agency. Decisions, both small and large, are open to change. As Sheila said, "Many times decisions we thought we had made, we reversed and changed based on the individual." This openness to change is a key part of what we mean by flexibility. As one staff member stated, "Part of the ebb and flow of life is to be flexible."

Larry himself is a source of creativity, another important aspect of openness to change. As one staff member said, "I don't know if other places are blessed with a man as creative as Larry...a sharp, smart man with a lot of creativity." It was Larry's idea to find apartments near neighbors or friends to try to provide the security and continuity some people need in their lives.

Larry hires people who are open to change and willing to learn. He also supports and encourages the ideas of other people thus encouraging a climate for change. As one staff member stated, "I have worked under Larry before and

felt his openness and support for new ideas." Or as another staff member explained, "changes are made based on suggestions people make." The organization learns from the experiences of its members.

As Larry explained, this approach is not without its problems. Allowing for creativity and flexibility also can create some disorganization.

MUTUAL LEARNING

In this organization learning is considered a mutual and ongoing process. Everyone is involved in learning from each other, including staff and people with disabilities.

> We talked how college students are learning more than the people we are serving. I am learning too. Things that are just dawning that I thought I knew a long time ago - rights, dignity.

The father of an employee of Pride Industries also echoed this same theme. He commented how much his son had learned in working here. Steve, who is quoted above, indicates how learning is ongoing; we can learn to understand even basic values differently over time. Brainstorming is encouraged in the organization and everyone's ideas are valued.

Most striking was the application of this value of mutual learning to the community-at-large. North Dakota has had a rapid pace of deinstitutionalization and it is now common to see people with disabilities in the community. One of the staff members spoke about the issue of the community learning.

> The community is learning more about what it means to learn together as a

people. And some of us will learn it and some of all of us will not learn it well.

In addition to mutual learning, this comment indicates an understanding that disability is not a personal issue but a societal one that must be addressed by community change.

REFLECTIVENESS

Tied closely with the theme of mutual learning is reflectiveness, an examination of one's own actions, thoughts and beliefs. Larry hires people who can look at the behavior of another person and say maybe the person is reacting to something I did or maybe there is a meaning I don't understand. Behavior is considered one way of communicating and the listener has some responsibility to figure out what the communication means.

This reflectiveness shows itself in many small ways. Sheila described how staff were not using some of the organizational tools she had created. She said "I think staff were saying to me they wanted to do it in an individualized way." This reflectiveness also seems to be an important way of understanding challenging behaviors and hearing what people are saying. As Sheila said, "Our success is because we listen to what the client has to say, even if they don't tell us directly."

This is a nontechnical, humanistic approach of relating to people, an approach consistent with current information on the importance of the communicative intent of behavior. In this agency, though, it is not part of a behavior management program, but a way of people being with other people.

"I VALUE YOU"

Larry particularly emphasizes the importance of valuing each person as an individual.

> Larry has taught me you never take anyone for granted. He makes people feel like they counted. He tells people why they are important, why they are appreciated as well as things they need to do differently.

This personal valuing leads to hiring staff who also value individuals, but may be very diverse in their backgrounds and abilities. This diversity is also a strength of the organization.

As Larry sees it, part of valuing people is standing by them when they make mistakes and trusting them.

> I know what Larry does for me. Whatever you say is credible. I will believe you and we will deal with it. You can't have fears of what your supervisors will think.
>
> They need to be supported - right or wrong. If they made a mistake, it was me who made the mistake. They make mistakes if they are not trained, etc. I need to own that.

Larry believes this trust is important at all levels within and outside the organization. Trust is also a key aspect of the program itself. As one example, staff keep track of their own hours. Larry says if you trust a lot, you get a lot back.

Jim, the other associate director, echoed the same theme, saying trust

and respect are characteristic of the organization.

> What impresses me the most, in spite of the problems which are inevitable, we are able to trust each other and respect the opinions of each other and we strive to do that better.

This trust and respect leads to a climate of mutual support. The management staff support each other and line staff feel supported by management. As June's program coordinator said,

> I think everyone gets along real good here. Everyone is willing to help everyone else no matter what their role, give each other ideas. We each have different experiences that help each other out.

CONSUMER CONTROL

Control over one's own life and decisions is another important aspect of this organization. As we talked about an agency where people with disabilities hired and fired their own staff, Sheila said, "Anything that puts more power in the client's hands, Larry would be interested in."

The importance of choices and decisionmaking also was a constant theme in the visits to people's homes.

> His mother asked David if he wanted to move back home with them. He adamantly shook his head no. He might move to an apartment in Minot, but David wanted to be in his own place.

George mentioned several times he decided to get a phone. I made a good decision.

Debbie wanted to live alone. She said it wasn't that she was hard to get along with. She now lives in her own apartment and it's worked out well.

The decisions people make extend to major issues, such as where and with whom they will live, as well as more minor items such as what to eat, where to store my things, and what to do on Saturday night.

This is not to imply that consumer's decisions are always followed in this organization. The team sometimes makes decisions conflicting with what the person him- or herself wants. Sometimes the person and the ISLA staff want the person to live in his or her own place and the team has not given their official blessing.

We considered a lot of places. A team decision, not good for George to live too close to Sarah, so we tried to compromise. He was mad as heck yesterday. He felt he had not made the decision.

During my visit, George's girlfriend Sarah confided she probably would be moving closer to his new apartment. People, including people with disabilities, have ways of reasserting their decisionmaking power when it is denied them.

Larry and Sheila understand individualization is not at heart a matter of individualized funding, but about consumer control and decisionmaking.

> The individuals we serve still have trouble believing they are doing this. People are still learning that we want them to have control over their lives. Just because a person is placed in an individualized placement doesn't mean that it will just be individualized.

At a time when individualized placement has become an "in" concept, it is refreshing to find an organization that is examining what this really means.

Individualization here means first and foremost a commitment to the individual person. For example, I asked what happens when the approved contract for the individual person has less than the hours the team thought was needed. One of the staff replied, "So far we have still gone with it. We've found ways to follow the decision of the team, not necessarily the way the team thought. We say to staff, do what needs to get done. Let us know the hours. Larry believes whatever needs to get done will get done."

Many of the staff in this organization recognize individualization is a commonly used word, but seldom represents a true focus on the individual person. As Steve said,

> I heard other people talk about individualization and customizing, but I've never seen it. It was always gingerbread. Pride ISLA delivers according to the needs of the individual.

Individualization in this organization is also supported by a variety of structural mechanisms such as funding. As one state administrator stated,

> Individualized contracts are the only way to do it. People talk about money following clients. We did it...allows for all sorts of

flexibility. ..It does not limit us to the number of beds or the type of client.

Individualized funding is one mechanism for allowing greater creativity and control by people with disabilities over their living situation. The critical decisions, including the selection of the home, the home's location and the roommates, if any, can be made by and/or with the individual with a disability. The home can reflect the person's unique hopes, needs and circumstances. Since the funding is available wherever people may live, people can live in typical homes in the community and receive more or less intense services based upon their unique needs and desires.

A SPIRIT OF OPTIMISM

This organization is also the story of the importance of hope, the belief in dreams, the love of one's work, the need for fun, and the importance of accepting who you are and feeling good about life.

Partially due to Larry's involvement in the mental health field, he brings to his job an understanding of the importance of people's attitude towards life and its effect on learning. In hiring new staff, he is less concerned with what a person is studying and more concerned about whether they are studying hard. He believes if a person has a good attitude about him- or herself and life, s/he can easily learn. As Larry explained, you "can't teach people skills if they feel bad about themselves."

A positive attitude toward self and life is seen as critical to a person's well-being. As one staff member said, "Debbie seemed so miserable to me....that was her disability. She was so miserable." It was not Debbie's disability, her head injury, that was viewed as a problem to overcome.

Instead, developing and maintaining a spirit of well-being is seen as one of her significant life tasks, a task we all share.

This spirit of optimism is also evident in the way they view success. Some of these successes may seem small when viewed from a distance, but as great accomplishments by those who know the person well. For example, June was able to gain control of herself at a very, very stressful time. She stopped herself and said "I'm calming myself down; I'm calming myself down." This was a big success for her and for the staff - a success worth celebration. As another example, Jerry, who had a history of violent outbursts and threats, learned he would be treated fairly and without vengeance. He responded to an unfair accusation without striking out and sought help from the police. This story is remembered as an example of all the day-to-day efforts coming together and making a difference. It was a great experience for both Jerry and the staff.

These successes are fostered by a spirit of hope. At one point, Larry explained he has not seen many meaningful, equal relationships between people with disabilities and community members. Thoughtfully, he added "but we must maintain hope." Even if a situation never worked out before, it may still do so in the future. Together with hope, there are also dreams. The ISLA program was not simply a new program; for some of the staff and people with disabilities, it was a dream come true.

Fun and enjoyment are also viewed as important. We shared laughter in almost every visit in people's homes. Sheila learned about helping people enjoy themselves from a manager at McDonald's. It is a lesson she carries with her. Even as an art teacher she tried to teach about enjoying life. To her this job is not much different than teaching art. Sheila wants people to have a better quality of life wherever they are, whatever the place, no matter what

their jobs or circumstances. Larry, too, feels enjoyment is an important part of living. "I enjoy what I do. I feel in touch with the meaning of life." Sheila also mentioned "if people love what they are doing, have an excitement about it, they will be good at it."

Many of the people here have relationships extending outside of work and enjoy being together. "We are all of the same bloodline. We know each other. We like each other. We fight and make up, go dancing.."

COMPROMISES, BARGAINS AND FINE LINES

The organization accepts compromise as an important part of life, for individuals as well as organizations. There are tradeoffs of all kinds in life. People here talk about the age old questions of how rights get balanced between people, where is the fine line between responsibility and rights, and how to balance individual and public needs. In describing George's struggles, Sheila said, "we hope he will see with responsibility comes greater freedom and choices. It's all bargains."

The fine lines are part of day-to-day decisionmaking. One area that is particularly difficult is leisure. People who lived in group homes may not have learned what to do with their leisure time in their own apartment. The fine line is the balance between exposing people to as much as possible without imposing on their leisure time. Another area is that of housekeeping. Some of the people in the program are good housekeepers and some people are more casual. The fine line is recognizing when there is a need to teach and when there is a need to let go. Staff members struggle with these kinds of issues everyday.

The issue of compromise also applies to the relationship between the staff and the organization. For example, one staff member said, "They cut back

on my hours when I needed it. I didn't have to fit into their way completely. We had to compromise." The issue of compromise is seen as an essential part of relationships.

PROBLEMS AND STRENGTHS: TWO SIDES OF THE SAME COIN

After talking with Sheila, Cory, Steve and Sandra about the strengths of Pride Industries, I asked about the problems. Steve replied that some of the things we just talked about were also the problems. I found this very impressive. The real problems are the larger issues - How can an individual emphasis be maintained as organizations grow? How can people with disabilities have more control over their lives? What do rights and dignity really mean? How can relationships be fostered? How can creativity be maintained? Asking these questions may be a key part of what keeps the organization vibrant and alive.

HOMEOWNERSHIP

Homeownership is used here to describe instances where a person with a disability has control over his or her own place either through sole or joint leasing or full or partial legal ownership.

In the ISLA program, a person can rent his or her own place either alone or with another person. On a practical basis the organization notes the following benefits of this approach. First, by renting one's own home, a person may be eligible for Section 8 housing assistance. Second, the tenant-landlord relationship is kept between the person with a disability and the landlord. Third, the home can be unlicensed; it can be less a facility and more a home. Fourth, leasing by the person with a disability is more consistent with normalization and typical of adult living in this society.

One important benefit of renting one's own place is the increased pride people seem to have in their apartment. As one regional manager stated,

> People I know are the people I see. People coming up to me and asking about things when they never did that before. Their face lights up about their apartment. When casemanagers come and visit they want to show the bedroom, the dishes, toaster...a kind of pride in ownership.

Some behaviors that were problems in group homes also changed when people moved to their own places. Part of this change was related to the increased independence and freedom in the apartments.

> People may have challenging behaviors in the group homes, but most disappear when they move to the apartments. People take pride in their places. They have more freedom and independence.

Other changes also occurred when people with disabilities moved to their own places. Some people described this as a change in the people (i.e., they grew and blossomed). Sheila explained,

> I've said that people grew by leaps and bound in the new environments. Actually they were that way all the time. The other environment stifled them. We just needed to let people be themselves.

ISSUES

STATE AND REGIONAL ADMINISTRATION

As described earlier, the ISLA program is one of the few examples in the country of an individualized service contract and funding process. Such funding which follows an individual can increase flexibility and take into account the uniqueness of each person.

In North Dakota the ISLA program was implemented to increase the movement of people with disabilities to less expensive residential settings. As one administrator explained, an ISLA contract will not be written if it can be done in a less expensive way. In practice, this has numerous implications, especially for people with severe disabilities.

First, based on the calculations of one regional administrator, it is not possible to support a person with severe disabilities who needs paid support on a 24 hour basis. This is not based on the funding mechanism itself, but on the administrative use of the ICF-MR yardstick for each individual living situation of one or two people.

Second, private service providers are expected to show a decrease in costs for each individual for almost every contract period. As one administrator stated, "If habilitation works, the costs should decrease." This concept is problematic since the basic assumptions behind this proposed reduction are inaccurate. While service needs for some individuals may decrease over time, for some individuals costs for services would be expected to stay the same and/or periodically increase. Even if decreases occur in services, the pace at which this occurs would vary markedly based on the individual.

Third, the expected decrease in costs from the private service providers

would tend to have the following effects in the service system: First, private service providers would be reluctant to serve people with severe disabilities, particularly people whose support needs vary dramatically over time. Second, such expected decreases would encourage providers either to prematurely reduce supports or to initially inflate costs to insure the person receives the supports s/he needs. One state administrator explained, they addressed the first potential problem by providing incentives to providers and the second through the use of external casemanagement.

Fourth, there is confusion about the relationship between restrictiveness, intensity of services and cost of services. One state administrator noted the ISLA program has produced a substantial cost savings to the state of North Dakota. He interpreted this to mean people were now less restricted because they received less services. Theoretically there is no direct relationship between restrictiveness and the cost of services or between the intensity of services and restrictiveness (Taylor, Racino, Knoll & Lutfiyya, 1987).

Fifth, although allowable under the federal home and community-based Medicaid waiver program, funds are not always easily accessible for items such as emergency response systems and are not available for in-home modifications, important funding inclusions for people with severe disabilities.

Sixth, people with disabilities may have limited resources for items such as clothing, apartment furnishings and recreation. These items are commonly considered in the field of developmental disabilities to be basic to the quality of people's lives.

Even with these concerns, the ISLA program has been a very positive step on the state level to support people with disabilities in the community. Prior to its implementation, people were placed in apartments with no or clearly

inadequate supports. Also people with greater needs had no other real option than a group home situation or their family's home. The new contracting process has also fostered an emphasis on the individual person, allowed for greater flexibility and been critical in the rapid deinstitutionalization of people from the state institutions.

COMMUNITY CONNECTIONS AND RELATIONSHIPS

Relationships and community connections are among the most complex issues in community living for all of us, including people with disabilities. This organization recognizes the importance of relationships in people's lives. However, the emphasis is on roommate relationships and those between staff and people with disabilities. There is relatively little energy placed on the development of friendships with community members without disabilities or on participation in community associations.

In a programmatic sense, there is a recognition in the ISLA program of the importance of the match between the staff and people with disabilities. For example, in talking about Debbie, one staff member explained "In her own apartment her self-respect and self-image have picked up. She dropped the mannerisms - shows them if things are not right - the lack of a respectful relationship, the right staff combination." The match between roommates is also considered programmatically critical. Increasingly people are involved in selecting their own roommates, although Larry sometimes acts as matchmaker.

As time goes on, people are choosing more to live together. If they move, they move for the same reasons anyone else would split.

One positive aspect of the relationship between staff and people with

disabilities is the stress on the mutuality of such relationships. For example, one staff member said, "Some people match better together with each other than someone else. It goes both ways - the staff and the people they are serving." These relationships, however, remain primarily staff-client ones. In addition, most of the staff are students and the relationships are likely to be short-term in nature.

Sometimes the relationships between staff and the people they work with, take on a dimension of friendship over time. Sheila described her relationship with Debbie.

> We've just become friends and we like each other. I don't have much of a sense of humor and her sense of humor is good for me. I've learned a lot from her. She taught me whatever you need to be you need to be consistent. Inconsistency in any service is really going to confuse her. Debbie is persistent. She persistently pursues. She is attracted to me and I to her - whatever that is. She wants to be in my life and she pursues me in that way. Over a period of time, it's become pretty equal. She pursued me as a staff person for awhile. I always treated her with the intellect and self-respect I think she had. I think she recognized that and liked it.

> The things important to me in my life are not happening with the same frequency for Debbie. I want Debbie to have relationships like we have with other people. She has relationships with staff from the agency. These are good but not enough. Relationships are a tough one. Sometimes it happens and sometimes it doesn't.

Isolation, however, continues to be a common experience. Living alone in an apartment or with a roommate may highlight the lack of relationships and community connections the person already was experiencing in the group home setting.

In group living situations, recreation and activities are often planned for the group and relationships are fostered primarily in-house. In a person's own place, the following questions seem to more easily arise. Who does the person want to spend his/her time with? What other people want to be with him/her? What does the person enjoy doing? When, where and how often does the person want to participate? What supports does the person need to participate? How can relationships and participation be fostered? Living in one's own place seems to bring out these kinds of questions - of preferences, of relationships outside the home, and of community connections.

The role of an agency such as Pride needs to shift to include a greater emphasis on the importance of people with disabilities becoming connected in the community and developing relationships with community members.

WORK

As mentioned earlier, Pride Industries is moving away from a reliance on sheltered workshops to supported employment. Most of the people I met, however, worked in a sheltered, segregated setting and expressed a desire for different and/or more challenging work.

> Debbie doesn't like her job. She stuffs envelopes and does labels. Debbie says she can make as little as $2.00 per month. She cut out an ad from the newspaper for a new job.

David likes woodworking, but he is not productive enough. Now he recycles cans and shreds paper.

Work is one of the major ways that adults meet other people in the community. The lack of community jobs may be one part of the isolation and lack of relationships that some people are experiencing.

The jobs described by the people I met also did not appear to build on their strengths. For example, David apparently has a wonderful sense of proportion and spatial relationships. Typical sheltered workshop or entry level positions in service work will not tap these abilities. David needs an actual job in the community modified to enable him to contribute the talents he has to the benefit of all of us.

It is important to mention that my visit did not focus on the area of work. The above comments, while critical to the lives of the individuals I met, may not be representative of Pride's efforts overall in the area of work. In addition, the lack of adequate funding for supported employment also seems to be a major issue facing the agency.

SUPPORTING PEOPLE WITH COMPLEX NEEDS

This organization is in the process of building its own capacity to support people with severe disabilities in the community. The continuum approach, including an emphasis on readiness (i.e., needing to prepare before living in a place of one's own) is still strongly emphasized by the state office and the agency. As Larry says people going to the ISLA program move out "a bit before their time." On a statewide basis, one person moving from Grafton can result in up to eight moves in the community. This is very disruptive to the continuity and relationships in people's lives.

Pride is dealing with some very complex issues in supporting people in the community including their relationship with the criminal justice system, working with the psychiatric community, and balancing risk and responsibility in areas such as sexuality. While some current practices are promising (e.g., the use of the individual justice plan, a personalized approach to the issue of sexuality, and education of psychiatrists), critical issues (e.g., the use of mild aversives, quality assurance mechanisms) still remain.

CONTINUED FUNDING

There is concern among private providers that the ending of the deinstitutionalization lawsuit will be accompanied by massive cuts in the human service budget in North Dakota. Pride believes the ISLA program is least in jeopardy because of its high profile, cost effectiveness, programmatic viability, and popularity among state, regional and local people. However, it is critical that the funding situation for community services and the effect on the quality of lives of people with disabilities be closely monitored. In addition, 250 people will still remain at Grafton, the state institution, after July 1, 1989, with no plans for their move to the community.

CONCLUSION

This case study highlights the connection between personal values and organizational practices. In addition, this report also profiles the lives of six individuals supported by this agency, describes the North Dakota home and community-based Medicaid waiver, examines the meaning of individualization, homeownership, and relationships in the lives of the people, and highlights selected issues facing this organization. It is important to note the case study describes only one program within a relatively large organization and emphasizes the positive aspects of the program.

I greatly appreciate the wealth of knowledge and experience shared during this site visit. I gratefully extend my thanks to each of the people who opened their homes and shared their insightful perspectives.

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For a description of the North Dakota Medicaid waiver:

Smith, Gary A. and Aderman, Sheila. (1987). Virginia: National Association of State Mental Retardation Program Directors, Inc.

or

North Dakota Department of Human Services

State Capital, Bismarck, North Dakota 58505